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Patient access to full general practice health records

The UK government's commitment to provide it should be realised

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Many countries empower patients to take on a larger role in their care by providing them with online access to their health records.^{1,2} Transparent records, and patient access to them, are also key to improving the safety of care.³ Approaches to sharing records differ internationally. Sweden rolled it out region by region from 2012.¹ The US mandated it nationally from April 2021.⁴ The UK government planned to do the same in England but its programme has foundered.⁵

NHS England's programme to provide citizen access to general practice records was due to go live in December 2021, following a 2019 pledge to provide all patients with full digital access by default by 2020.⁶ But launch was put back to April 2022 and then 1 November, after the Royal College of General Practitioners said practices needed more time and training to implement it.⁷ In July, the college updated its online services toolkit and NHS England circulated guidance and resources for general practice staff based on the experience of 16 early adopter practices.^{8,9}

Two days before the 1 November deadline, the BMA called for a total rethink of the programme.¹⁰ Practices who were not ready to implement it asked their software suppliers (most use EMIS or TPP) not to enable default access. In December, one supplier (EMIS) restarted the default access option, but NHS England has told us that only a minority of practices will be enabled by the end of 2022 (personal communication). It remains unclear when default access will be available for everyone.

Patients left in the dark

Most patients are unaware of NHS England's programme and its delayed implementation. Policy makers and clinicians claim to be acting in patients' best interests, but patients have largely been left out of the conversation. What they do know is that access to personal health information varies appreciably between general practices, while some NHS trusts already provide access to secondary care records, mostly through the PatientsKnowBest platform.¹¹

Patients have a legal right to their health information.¹² But those who request it often face barriers or are given only limited data.¹³ Clinicians opposed to record sharing by default often argue that few patients want it and many lack the skills to take advantage of it. But the covid-19 pandemic has increased public interest, and the Patients Association reports high traffic to its online guidance on how to access records.¹⁴

Half the UK's population have the NHS app,¹⁵ using it to access NHS covid passes, order repeat prescriptions, view messages, and see part of their general practice records, including immunisations

and prescriptions. Other information—including consultations, hospital communications, test results, and free text entries—is technically accessible through the app, but most patients have not been “enabled” to see it, and many are unaware that this is possible.

Evidence is supportive

The UK is behind the curve on access to patients records and on evaluation. The OpenNotes movement in the US has been tracking its effect for a decade.¹⁶ The Swedish based DOME consortium (Development of Online Medical Records and E-health Services) has published over 100 research studies (mostly surveys and qualitative designs) evaluating the effect on patients and health professionals.¹⁷

Evidence shows that access to notes helps patients understand their conditions, remember management plans, prepare for consultations, and take more control of their health. Patients can identify errors and omissions in health records, which are worryingly common,¹⁸ and bridge information gaps between providers. A recent narrative systematic review of 74 mostly observational studies reported substantial benefits and evidence of improved outcomes.¹⁹

Earlier, more open, and inclusive debate might have convinced more of England's overstretched GPs concerned about workloads, safeguarding, and their liability as data holders and controllers, to roll out access to records as planned. They have the facility to block access for patients judged to be vulnerable and redact elements of any electronic record. Experience from the US, where clinicians expressed similar fears initially, is reassuring.¹⁶ Transparent records may help reduce litigation and malpractice²⁰—and may also save GPs time.⁹

Incomplete and uneven access to personal health information makes little sense to patients and their carers. Lack of timely access adds to their healthcare burdens.²¹ Access to records and the opportunity to use them for interactive exchange²² could benefit most patients, particularly those with long term conditions. Resources for clinicians and patients on how to adapt to a new world where electronic health records are a shared resource are available.²³

With access to care in the UK among the worst in Europe,²⁴ patients have little choice but to be more self-reliant. Ready online access to their full health record would help them and also reduce demand on the health system.²⁵ The commitment to provide it should be realised.

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